

FINAL ECCP PARENT INTERVIEW REPORT

Final Evaluation Report

Early Childhood Connections Program (ECCP)

Parent Interviews

5/10/12

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Executive Summary

- Guardians referred to developmental or behavioral programs through the Early Childhood Connections Program/Linkage Coordinator (ECCP/LC) were interviewed to assess use and satisfaction of services. There were 118 guardians were initially referred to ECCP between March 2010 and June 2011; 20 were interviewed and received a \$20 gift card.
- ECCP/LC referred guardians to a total of 26 services/programs. Most of the referrals were for hearing/speech evaluations (54%); the remaining were: behavior management (15%), child counseling (12%), parenting classes (8%), special education (8%), and day camp (3%).
- Six out of 10 referred to Early Intervention (EI) received hearing/speech or behavior management services. Three children did not receive an evaluation because the guardians thought their child was too young or saw improvement and decided they did not need EI services. Only one child was evaluated but determined to be not eligible for services.
- Fifteen guardians remembered ECCP/LC: all guardians thought they were contacted soon enough after the pediatrician's appointment, felt comfortable and understood through ECCP/LC, and that explanations of services were helpful.
- Most of the guardians already had concerns about their child's development and agreed with the referrals they received. Those that did not thought their child was too young or wanted to "wait and see" how their child's speech or behavior progressed on their own.
- Fifteen (out of 26) referrals were considered complete linkages (child or guardian completed at least an evaluation appointment and/or participated in the program they were referred to by ECCP/LC). In addition to wanting to "wait and see", some families were moving or experiencing other transitions that prevented them from seeking or continuing services.
- Most guardians gave overall positive reviews of ECCP and thought services they were referred to were helpful. Some reasons why some guardians thought services were not helpful were that their child was evaluated, but determined not eligible for services, or the doctors involved would not try medication as a treatment option.
- All but one guardian thought the follow up call from ECCP/LC was helpful. Only one guardian knew for sure that ECCP/LC gave the pediatrician information about the services they were referred to. Fourteen guardians discussed the progress or outcome of these services with the pediatrician.
- All (except for one maybe) guardians would use the linkage service and also recommend it to another parent if it was listed as toll-free telephone number to call in with concerns about behavior/development and to receive information about services.
- Suggestions to improve ECCP were more follow up calls (3 or 6 months post-ECCP/LC referral) to see if services are satisfactory or if other services are needed, or to offer a "preview" of the service being referred to for the family to see if they want to participate.

Introduction

The Early Childhood Connection Pilot Program (ECCP), in partnership with pediatricians in Erie and Niagara Counties, identified children at risk for developmental or behavioral issues. The ECCP Linkage Coordinator connected guardians and their children with appropriate services for evaluation and treatment. With the help of a grant and technical assistance from the Kellogg Foundation, ECCP will be transitioning into Help Me Grow Western New York (HMG WNY). Help Me Grow is a national movement to create processes for identifying and connecting children and their families to services. The purpose of this evaluation is to further understand the family's experience of ECCP, and to use this information to assist in the transition into HMG WNY. The study questions to be answered by this evaluation are:

- Did the doctor or healthcare provider explain to the guardian that they would receive a call from the Linkage Coordinator?
- Were the services families were referred to appropriate for their needs?
- Did families access the services they were referred to through the Linkage Coordinator? If no, why not?
- If the family accessed services, were the services useful?
- Did they receive a follow-up call from the Linkage Coordinator? If so, was this useful?
- Do they know if their physician received any information about the referrals from the Linkage Coordinator?
- Did they discuss the services they received with their primary care physician?
- Is there something else that they needed that they did not receive?

Methods

The Early Childhood Connections Program (ECCP) parent semi-structured interview guide was developed by the program evaluator, Sarah Kuszczak, utilizing ECCP materials, previous Help Me Grow (HMG) Orange County parent survey, and HMG brochures and resources. Representatives from ECCP and HMG WNY committees provided feedback on the interview guide. The final version of the interview guide can be found in Appendix A. This evaluation is funded by the Community Health Foundation of Western and Central New York.

I obtained the ECCP Microsoft Access database from the Linkage Coordinator (LC). The database contained: guardian and child names, child gender, child date of birth, child age, address, telephone number, identified concerns/developmental issues, services referred to, barriers to contacting or referring the family, and qualitative record of linkage coordinator contact with the guardian. I called the most recent completed referral, and called guardians in reverse succession. Calls were conducted late morning, afternoon, and evenings in order to reach a wider range of guardians. I kept track of all calls with a Microsoft Excel spreadsheet, and stopped calling a guardian if no contact was made after four attempts. Initial pediatrician's office referral dates of those contacted (and also of those interviewed) ranged from March 2010 to June 2011. One hundred eighteen guardians were considered for contact, including guardians in the database that were not contacted because they did not have contact information listed or their telephones were disconnected when the LC tried to contact them. Phone calls took about 2.5 months to complete. Guardians that completed the telephone interview were mailed a \$20 gift card of their choice to Tops or Wal-Mart. Table 1 below shows the outcomes for the 118 guardians considered for contact.

Table 1

Contact Outcomes

Outcome	N	% of total considered (118)	% of total contacted (76)
Completed Interview	20	17%	26%
Not reachable/refused (wrong #, phone disconnected, no answer)	56	47%	74%
Were not contacted by/refused referral from Tanice (Evaluator did not contact)	42	36%	N/A

Out of the 20 guardians who completed interviews, 18 were the child's mother, 1 was the child's father, and 1 was the child's grandmother. I created separate interview guide documents for each guardian and typed notes in the document during each telephone interview. I created a Microsoft Excel spreadsheet which included all of the interview questions. After each interview, the answers to each question were entered into the spreadsheet. After completing the interviews, each guardian's interview guide document was checked against the spreadsheet to ensure accuracy. This Excel spreadsheet was used to create this report.

Results

The results are divided into five sections: Pre-Referral, Referral Process Through ECCP, Post-Referral: Receiving Services, Post-Referral: Follow-up, and Guardian Suggestions.

Pre-Referral

This phase featured questions asked about receiving information about the ECCP/LC from the child's pediatrician's office and knowledge of Early Intervention services before ECCP referral (if applicable). There were 15 out of 20 guardians who remembered receiving information about ECCP from their child's pediatrician's office. Three guardians did not remember, and two guardians were connected with services via daycare referrals. Qualitative data gathered from this question is as follows:

- "I wanted information about speech therapy for my son; I talked to doctor about it, and got the referral."
- "We [parent and doctor] were both concerned about my child's speech not developing right."
- "Yeah, they told me that I would have somebody to work with to figure out what programs would be best for him...that was enough information for me."

Early Intervention

Ten out of twenty guardians (50%) were referred to Early Intervention (EI). Five of these guardians knew what EI was at time of ECCP referral. Only one of these guardians was formally referred to EI by another doctor about five months prior to ECCP referral, and two other guardians had friends that suggested they contact EI. Even though these three guardians were previously referred (either formally or informally through a doctor or friends) to EI, they were only successfully connected with EI through ECCP/LC referral. A sample of explanations given about EI from the linkage coordinator:

- "That two women would come out to house to evaluate my child and give help as needed to him."

- "It's for the benefit of the child, to see if there's any speech problems, to get them help early and make sure she's speaking correctly. There's nothing against me."

All EI referrals were for speech/hearing evaluations, and one also included a referral for behavior management as well. Out of the ten guardians referred to and contacted by EI, three did not receive an evaluation because the guardians thought their child was too young or decided that their child's speech improved enough to not seek EI services. Only one child was evaluated but determined to be not eligible for services, and the remaining six children received services through EI. In addition, two of these children were referred to other agencies for continuation of speech services after exceeding the age limit of EI (age 3).

Referral Process Through ECCP

This phase featured questions starting with the initial phone calls with the ECCP/LC, the quality of these interactions, and the amount of agreement and understanding by the guardian for the referral(s). For those that remembered ECCP and speaking with the LC (15/20), all stated that they were contacted soon enough after the pediatrician's appointment and that they felt comfortable and understood by the ECCP/LC. They also thought that the LC's explanation of the referral was helpful. The following are some specific guardian comments about the quality of interactions with the LC:

- "Just the fact that she understood I wanted my daughter in a program to get her the help she needs. She went out of her way a little bit too."
- "She was very nice and professional."
- "Nothing really in particular, just that they had a lot of programs that I could choose from, I wasn't too comfortable w/ him [child] going right into counseling, everything was straight forward and she [LC] laid everything out for me."

- "She was on top of things and I appreciate that."
- "Just friendly atmosphere over the phone; she followed up afterwards."
- "He had behavior issues. I was looking for a mentorship, [the LC] found me someone who could hear my baby's problems and help him with what's on his mind or bothering him."

Out of all of the guardians (regardless of whether they remembered ECCP/the LC or not), there were only two guardians that did not agree with the purpose of the referral, either because they thought their child was too young to be concerned with speech or did not think their child needed services at that time. Many of the guardians that did agree with the referral were concerned about their child's development, for example:

- "He was only able to speak mommy and daddy, so I knew he needed help."
- "I wanted my son to be evaluated for his problem behaviors at daycare, but I wasn't seeing these behaviors at home."
- One guardian stated several times she has raised many children and knows when things aren't right, so she knew her child needed help.

Post-Referral: Receiving Services

This phase included service/program referral outcome and satisfaction. Guardians referred to Early Intervention and Special Education were also referred to the Early Childhood Direction Center (ECDC) for extra parental support via mailed information packet. Only 2 out of 11 guardians remembered receiving the packet, but neither guardian contacted ECDC and did not give a reason for lack of contact. No further inquiries occurred regarding these referrals, and are therefore excluded from further analyses.

Table 2

Service/Program Referrals by Category

Service/Program	Number (total = 26)	% of total referrals
Hearing/speech	14	54%
Behavior Management	4	15%
Child Counseling	3	12%
Parenting Class	2	8%
CPSE	2	8%
Day camp	1	3%

Fifteen guardians received 1 referral, four guardians received 2 referrals, and one guardian received 3 referrals. The LC initiated contact for those referred to EI; all guardians were contacted by EI. There were four guardians that did not contact any services; one of these guardians was referred to two services. Both guardians that were referred to parenting classes did not remember receiving this referral and did not contact these programs. Reasons for not contacting other programs were:

- "I just wanted to wait things out. I was kinda scared, I don't know what they were going to think. She was going to be starting kindergarten, and the teacher said 'I could let you know if I think she has ADHD.'"
- "We never went to any programs. I would like her to, she still has a problem. I was thinking at the time 'oh its her age, she's 6 years old.' I think she has an attention deficit or a sensory problem or something...The time frame was bad- I was working; I didn't think she needed services. I thought it was her trying to get

comfortable because she was moving, I didn't think something was wrong with her. She throws temper tantrums. She's in school, in kindergarden- an excellent student at school, at home is the problem."

- "I was pregnant and I had about a month to go at the time."

Out of the 21 remaining program referrals, four guardians that were contacted by EI chose not to have their child participate in the program, and another two guardians who contacted the program but did not participate. Overall, 15 program referrals could be considered a successful linkage. Reasons for not participating in the referred program were:

- "I wanted to work with my son on my own to see progress."
- "Because of her age it was hard to tell if it was an attention thing, didn't want that label [ADHD] being with her for the rest of her life."
- "I moved so I'm still readjusting to that. This is a new year so I will have to contact them to see if he can get services."
- "They said I had to be a teen mom for my kids to go, so we didn't do it."
- Not able to afford program.
- When EI called, guardian decided son's speech was normal.
- Another family was in the process of moving.

Out of the 15 children that participated in services, six of them were still participating in the program at time of the phone interview. Reasons given for not continuing services were:

- "I met with them [child counseling]. They were just too strict for me, I didn't like the way they were talking. It wasn't what I expected. I didn't feel comfortable. I just met with them once."

- "The last time was a couple months ago- probably around November. My mom died in early December, and things started to get hectic with school, classes and finals for me."
- "We went for a year, it did no benefit for my daughter, and they wouldn't listen to anything I was saying. Since she's good in school, they couldn't see how there's a problem at home- she's gotten us kicked out of Tops, she beat her father up in McDonald's. She was seeing this guy [counselor], he does see she has problems with attention, but just because teachers kept giving a good review of her, he didn't help her, so I took her out of there too. I'm sick and tired of people who are supposed to help but don't."
- Child was evaluated, but deemed not eligible for services.
- Completed EI because of age, was referred to CPSE or other agency to continue.

Out of those who participated in services, eight guardians found the programs to be helpful, three did not, and three guardians had mixed reviews. Comments from those who said services were helpful:

- "Everybody can understand her now. I was able to understand her before, but now everyone can."
- "He's saying ooohs and ahhs and making animal sounds now. He's 2 now. It's hard for me, because I think something is wrong with me, ya know? But I know it's just his own mentality or mental abilities."
- "They think it's only minor frustration- frustrated because he can't do what other kids can do, his verbal abilities are good, but they're concerned because he loses focus and concentration easily. They have to keep him entertained since he's so

smart, that he might get bored real quick. He's bigger than the other kids- he stands out more because he's a bigger kid. Maybe teachers notice him more."

- "He's saying bigger words, talking better, doing a lot better now."
- "When he first began, he was a little nervous, started a little slow, but he's learned a lot from the program. He's really grown. Everyday, he learned new words, like new sentences, colors, he learned his animals. He's really improved. I'm happy. Unfortunately he couldn't keep going after he was 3. I'm very satisfied."

Comments from guardians who had mixed comments:

- "Last year Headstart was helpful, mostly for my daughter- she had really great teachers, but things weren't really that great for my son this year, programs not all that good- there's a lot of behavior issues for other kids that is disruptive for him."
- "It seemed to be working, his behavior was terrible. It got better, then got worse again. I took some measures that the counselor wouldn't have recommended, so we'll have to wait and see what happens."
- "The person worked with teachers to set up reward program with stickers, it worked for awhile, but the teachers stopped utilizing it after the person left. My child also caught on and the program no longer worked."

Comments from those who did not think services were helpful:

- "They're [doctors and counselors] so against doing anything to really help her- they say she's too young to put her on something [medication], I'm just asking for a trial."
- Child was evaluated but not deemed eligible for services, parent disagreed.

Post-Referral: Follow-Up

This phase includes ECCP/LC follow-up with the guardians and referring pediatrician's offices. Out of the fifteen guardians that remembered ECCP/the linkage coordinator, 10 stated they received a follow up call from the linkage coordinator, and 5 stated they did not remember if they did or not. When asked whether this was or would be helpful, guardians said:

- "Probably just to let her [the LC] know my child is where she needs to be."
- "Very much so, seeing that I have a lot of stuff going on right now."
- "I was happy to see that she checked in on us and made sure everything was going well."
- "It was so nice that she did. I'm a case manager so I know people get lost in the shuffle sometimes. It's nice to know she cared and that the primary issue is not being ignored."
- "I think she called maybe two months later, and asked if I went to any programs. I told her I didn't contact anybody, just trying to wait it out. I was waiting for her [child] to start kindergarden."
- "Yes, because had I been in the program or wanted something else, sometimes you don't think of it on it your own."
- "No, because she wasn't the one who evaluated my child."

Only one guardian knew that their child's pediatrician's office received referral information from the ECCP/LC. Seventeen guardians did not know or were not sure if this occurred or not, and two guardians said they were not referred for services as a result of a pediatrician's office visit (as previously reported above). It is important to note that one pediatrician's office relocated during this time period, and many guardians switched providers.

When asked whether or not follow-up calls by the ECCP/LC were or would be important, responses were:

- "I'm not sure. The speech therapist asked if she could give the doctor results, I said it didn't matter, so I don't know if the doctor knows."
- "Not really. That seems like it'd be my job."
- "Yes, I would like that."
- "To do better job in assessment, it would be good to get physician's input to better help my son. You sometimes have to get outside of job description to get job done, to try to get the best services possible."
- "I don't know, the new pediatrician's office said something about counseling and parenting classes, and they referred us to the JCC."
- "It would probably be helpful, but she only goes to the doctor once a year."
- "Yeah, to see if there is any improvements or stuff."
- "Not really because there's nothing they could do. Well, I'd have to say yes because if it was not behavioral, then I would have wanted them to know about it in case I needed something else, like to evaluate him for ADHD."

Fourteen out of 20 guardians had discussions about satisfaction with and progress of their child in the services with a provider at the pediatrician's office, nine discussions were initiated by the provider, and five were initiated by the guardian. Descriptions are as follows:

- "The physician's assistant asked if we were hooked up with services. I let her know yes, she was happy to hear that. That was really it."
- "The doctor said 'He's just like any other kid. Looks like he has some behavioral problems.' He wasn't very helpful."

- "They [pediatrician's office] were already aware, they are in contact with his occupational and speech therapists."
- "It was a while back, they asked how things were going, and he was doing a little better."
- "When she started kindergarten, that's when I told him [doctor], he asked about her behavior, I told him she's calmed down a lot and not throwing tantrums, and I just want to see how she acts in school."
- "One time they asked, and I told him he was enrolled and it was going good. He got shots and it was over 3 months ago. If they bring it up next week, I'll bring it up that I had to stop because of family crisis."
- "I brought it up to them and by then the behaviors had resolved."
- "They wanted her to start seeing [counselor] again, but I'm hesitant. I'm not going to waste my time and money when they're not going to do diddly squat for her."
- One guardian discussed the results of the evaluation with the pediatrician, who agreed that child should have services and said the child should get re-evaluated in three months.
- Another guardian assumed the doctor's office knew because child is now in public school and his service got switched.

Guardian Suggestions

This section included summative guardian comments and suggestions for the future. All but one guardian reported that if the linkage service was advertised as a toll-free number, they would use it and recommend it to a friend (one guardian said maybe). Comments were:

- "I would call if things got out of hand."
- "Because if it were not for my education or job, I would not know about services in the area. There's a lot of young mothers out there, so it would be good to have information around."
- "Some parents aren't good parents and don't work with their child, so I would tell them to use it and call."
- "The only way I could answer that is if they didn't give me the same stereotypical answer all these years."

When asked if there was something else the guardian or their child needed but did not receive, only three guardians said yes and two guardians said they were not sure. Specific comments are as follows:

- "He still needs a mentor, a male encouragement figure, I looked into it but it didn't happen. Maybe some after-school tutoring too."
- "I still think he needs speech therapy."
- "I don't know. I wish the doctor knew more about ADHD instead of having to refer her somewhere else. I didn't like the whole idea of someone else talking to my kid."

Some parents had further suggestions to improve ECCP/linkage service, such as more follow-up phone calls and offering a preview of possible services. Some of the specific suggestions were:

- "A call every now and then to check in on things, to see if we needed anything, maybe once every three or six months."

- “Maybe just checking up a little bit more, touching base, asking if there is anything different they could do or any other services that I needed.”
- "I think it's a good idea to put the number up in the office for doctors to refer parents there."
- “I don't know, maybe doing some kind of a preview of services before signing up for services. The woman kept calling me after, maybe they could set it up to get a watch in before setting up an appointment to going there. Then I don't have to get harassed from them.”
- “To have one of the ladies or doctors at the counseling place to come to the home, or have the doctors go behind the glass with the counselors and view the interactions between the child and adults. The counselors don't remember everything that goes on- they should give them [child] situations and see how they react. They're just sitting there watching the kid play with a new toy house. The counselor I had never even had children. It takes experience, not just nieces or nephews. I think they should have prolonged experiences, like having kids, before being a counselor.”

At the end of the telephone interview, guardians were asked if they had any other comments or anything else they thought would be important for the evaluator to know.

Comments are as follows:

- "Nothing, they did a pretty good job."
- "I think they've done what they could, and everything is working out as it should be."
- “I'm not sure. I think they're doing a pretty decent job.”

- “I had a great experience and I am grateful.”
- "It was a positive experience, nothing negative to report at this time, everyone was professional, courteous, and patient."
- "I felt comfortable, and I didn't take it personally. They did awesome by letting me know it exists."
- "I think it was a lot of help and he really enjoyed it."

Conclusions/Transition to Help Me Grow

Only 20 of the most recent 118 guardians referred to ECCP were interviewed, and these guardians who were reached more easily and participated in these interviews may also be those that were more satisfied with services. It is possible that this sample may not be representative of all of the guardians referred to ECCP. However, most of the guardians seemed to be satisfied with ECCP and the programs they were referred to, especially when the family followed through with participation in these programs. For those families that did not participate in any programs, reasons seemed to cluster around common themes. Some families were going through a transition, such as moving. As previously mentioned, one pediatrician's office relocated, which often caused a disconnect between old and new providers. Another reason that some guardians did not receive services was because they wanted to “wait and see” if speech or behavior improved with their children. Some children did improve, but some guardians may lack awareness of the importance of (early) intervention in these domains. There was also a subgroup of guardians that did not want their child to be given a label early on, possibly reflecting a perceived stigma of mental health or behavioral treatment. Similarly, another finding of interest was that those guardians referred to parenting classes did not remember receiving these referrals and therefore did not follow through with them. Perhaps parents did not see themselves as

needing help, or felt threatened or offended by someone suggesting they needed parenting skill improvement. Future referrals should use language to take the focus off the parent and place emphasis on helping the child.

All but one guardian stated they would use a toll-free telephone number to call in with questions about child development and to help find services, and also would refer a friend. While this is certainly positive, these questions may not represent actual future behavioral outcomes. Similar to the implementation of ECCP, physician encouragement of this toll-free telephone service may enhance parent awareness and willingness of use, and therefore effectiveness of the transition into HMG WNY. The most prevalent suggestion for improvement from the guardians were more follow-up phone calls, particularly some time after beginning the program to which they were referred, to see if other referrals were needed for the family.

Appendix A
ECCP Interview Guide- final
1/17/12

Script: “Hello, may I speak with **[name]**?”

If parent not available, ask When would be a better time to reach him/her? [Set up day/time to call back.]

If someone other than the parent answers/asks who I am or why I’m calling: My name is Sarah Kuszczak and I’m calling from the Early Childhood Connections Program and would like to speak with **[name]** about his/her opinions of this program. When would be a better time to reach him/her? [Set up day/time to call back.] Mention gift card as a thank you for their time if they inquire further.

If yes, continue:

My name is Sarah Kuszczak and I am calling to ask you some questions about the Early Childhood Connections Program and the linkage coordinator, Tanice Pendergrass. This should take 20 to 30 minutes, and you’ll receive a \$20 gift card to your choice of Tops or Wal-mart as a thank you for your time. Is it ok if I ask you some questions about the program?

If no, ask Is there a better time to reach you? [Set up day/time to call back.]

If yes, continue:

To refresh your memory, you may remember being contacted in **[month]** by Tanice Pendergrass, the Linkage Coordinator for the Early Childhood Connections Program. Your child’s doctor’s office referred you to Tanice because they thought your child/ren **[name/s]** might benefit from services or programs, such as **[service/program name/s]**. Tanice’s job as linkage coordinator was to find those services for you/your child/ren and make sure they were appropriate for you/your children, and to contact you about these services. I would like to ask you some questions about whether or not having a linkage coordinator like Tanice was helpful to you in finding services and programs for you/your child/ren. Also, I’m interested in hearing if you used the services and whether or not you found them helpful. This information will be used to make this program easier and better for other parents. Your answers will be kept confidential, meaning Tanice, your child’s doctor’s office, and any other agencies you have used will not know how you answer these questions. I will be asking other parents their opinions as well. Do you have any questions before we begin?

First, a question about your child’s doctor’s office.

1. Do you remember someone, such as a nurse practitioner, physician’s assistant, or doctor, at your child’s doctor’s office explaining that you would receive a call from Tanice/the Linkage Coordinator? Y/N
 - a. If no, ask What information would you have liked to hear from the doctor’s office about this process?

- b. If yes, ask Did they explain why Tanice/the Linkage Coordinator would be calling you? Was this explanation helpful? Was there any more information you would have wished to hear from your doctor's office about this process?

[If referred to Early Intervention:

- 2. Before Tanice referred you to Early Intervention, did you know what Early Intervention was? Y/N
 - a. If no, ask Did Tanice describe Early Intervention to you?
 - i. How did she describe Early Intervention to you?
 - b. If yes, ask Where did you learn about Early Intervention?
- 3. Before Tanice referred you to Early Intervention, had anyone ever suggested you contact Early Intervention?
 - a. If yes, ask Who suggested Early Intervention to you before?
 - i. If it was child's doctor/NP/PA, ask Was it at or around the same time as Tanice's referral?
 - ii. Did you contact Early Intervention at that time? What happened?]

[If referred to Early Intervention and/or Special Education:

- 4. As part of being referred to Early Intervention or special education, you were also referred to the Early Childhood Direction Center. Did you receive their information packet in the mail? Y/N]

Now I'm going to ask you some questions about your conversations with Tanice/the linkage coordinator and the services you/your child may have received. Remember that Tanice and any agencies that provided services will not know how you answered these questions.

- 5. Do you feel you were contacted by Tanice in a reasonable amount of time after you child's doctor's appointment? Y/N
 - a. If no, ask What amount of time would you have liked to be called in?
- 6. Did you feel comfortable talking with Tanice/the Linkage Coordinator?
 - a. If no, say I'm sorry to hear that. Why didn't you feel comfortable talking to her? What could she have said/done to put you more at ease?
 - b. If yes, ask Was there anything in particular she said/did to make you feel comfortable?
- 7. Was Tanice/the Linkage Coordinator understanding and attentive to your/your child's needs? Y/N

- a. If no, say I'm sorry to hear that. What could she have said/done to make your experience better?
- b. If yes, say That's great. What specifically did she say/do that was most helpful?

[Note: Questions 8-13 will be asked for each service in which family participated]

8. Did Tanice/the Linkage Coordinator explain the reason for the referral to **[agency name]**? Y/N
 - a. If no, ask Did you already understand the reason? Did you ask why the referral was being made?
 - b. If yes, ask Did the explanation make sense to you?
9. Before contacting **[agency name]** (or before Tanice contacted for EI), did you think **[service]** was the right service for your/your child's needs? Y/N
 - a. If no, ask Why didn't you think they were appropriate? Did you ask Tanice about what other services might be more helpful?
 - b. If yes, ask Were you looking for something like [service] before you were referred to them?
10. After Tanice referred you to **[service]** at **[agency name]**, did you contact **[agency]** to obtain more information and set up an appointment?
 - a. If no, ask What stopped you from contacting [agency]?
 - b. If yes, ask Was it easy for you to gain information/make an appointment?
11. Did you/your child participate in the **[service]** at **[agency]** you were referred to by Tanice/the Linkage Coordinator? Y/N
 - a. If no, ask What stopped you from using these services? **Skip to #14.**
 - b. If yes, continue below.
12. [Depending on services] Are you/your child still participating in **[service]** at **[agency]** you were referred to by Tanice/the Linkage Coordinator? -or- Did you/your child complete **[service]** at **[agency]** you were referred to by Tanice/the Linkage Coordinator? Y/N
 - a. If no, ask What stopped you from continuing/completing [service]?
 - b. If yes, continue below.
13. Do you think this **[service]** is/was helpful?
 - a. If no, ask Why not? What would have made it more helpful?

- b. If yes, ask How was it helpful? Do you see differences in how your child behaves/acts?

- 14. After referring you to **[service]**, did Tanice/the Linkage Coordinator call you back?
 - a. If no, ask Would this have been helpful?
 - b. If yes, ask Was this helpful?

A part of Tanice's job/this linkage service was to build a better relationship between you, your child's doctor's office, and the services/programs your child was referred to. I would like to ask you a few questions about what has happened since receiving the referrals.

- 15. Do you know if your child's doctor's office received any information about the referrals for **[agency]** from Tanice/the Linkage Coordinator? Y/N
 - a. If yes, ask What kind of information did they receive?
 - b. If no, ask Do you believe that this is/would be important?
- 16. Did some at your child's doctors office, such as your child's doctor/NP/PA bring up **[services]** at **[agency]** in discussion with you to see how it went/was going? Y/N
 - a. If no, ask Did you discuss the **[services]** at **[agency]** you/your child received with your child's doctor/NP/PA?
 - b. If yes, ask How did this discussion go?
- 17. If this linkage service were advertised in your doctor's office as a toll-free telephone number to call in with questions about your child's behavior or growth/development and to obtain information about services for your child, would you use it? Y/N
 - a. If no, ask Why not?
- 18. If this linkage service were advertised in your doctor's office as a toll-free telephone number to call in with questions about children's behavior or growth/development and to obtain information about services for children, would you recommend it to another parent? Y/N
 - a. If no, ask Why not?

OK, now I would like you to think about the experience as a whole, from your doctor/NP/PA's office, to receiving referrals from Tanice, and going to **[services]** at **[agencies]**.

- 19. Was there something else that you felt you/your child needed that you did not receive? Y/N
 - a. If yes, ask What additional services/information would be helpful?

20. What else you could think of that would make the linkage coordinator service more helpful or useful?

21. Is there anything else you would like to tell me or think I should know about your experience being referred to [services], or the [services] you were referred to?

Thank you very much for answering these questions! This information will help us develop and expand this program for children and parents in WNY in the future.

[Confirm mailing address for gift card, and ask whether prefer Tops or Wal-Mart]